Utah Digital Health Service Commission Meeting

Thursday, March 4th, 2021, 10:00 a.m. – 12:00 p.m.

Utah Department of Health

Minutes

Members Present: Mark Dalley (Chair), Seraphine Kapsondoy-Jones, Sarah Woolsey, Dallas Moore, Matt McCullough, Preston Marx, Rand Rupper, Kenneth Schaecher, Trish Barrus, Chris Klomp, Henry Gardner, Brian Chin, Ben Hiatt, Todd Bailey

Staff Members: Navina Forsythe (UDOH), Humaira Lewon (UDOH), Huaizhong Pan (UDOH), Robert Wilson (UDOH), Valli Chidambaram (UDOH)

Guests: David Cook, Sid Thornton, Sarah Knight, Mark D Hiatt, Mathew Ahern, Cheyanne Anderson

Welcome and Introduction:

Mark Dalley welcomed everyone, and there were brief introductions. January 2021 minutes were motioned for approval by Preston Marx, and Sarah Woolsey seconded. All voted in favor.

Seraphine Kapsondoy-Jones was introduced. She is the Chief Clinical Information Officer at Intermountain Health Care. She is over Nursing and ancillary services, HIT, digital health, and patient-centered care

Sarah Woolsey was previously with Comagine Health and is now the Director of the Division of Family Health and Preparedness at the Utah Department of health.

Review of DHSC Law

Navina reviewed the laws of the Digital Health Services Commission. The committee has a duty to advise and make recommendations of digital health services. The committee had previously made a recommendation of interoperability and data sharing with behavioral health. Modifications to 42-CFR have been seen. There was formerly a recommendation for the department to take an official stance on an e-signatures policy. Navina read through other duties outlined in 26-9f-104. Many of the committees' responsibilities are done through the State HIT plan. They have been working on a social deterrence of health initiative that the governor and legislature supported. Navina has a role of passing up recommendations related to the committee to executive leaders and the governor's office and legislature. A majority of the committee has recommended to continue the commission.

The Landscape for Using and Sharing Genetic Information

Rand Rupper introduced the topic and the speakers - Mark D Hiatt and Sarah Knight. Mark presented first. He is a cardiologist at Regence and has experience with genotyping in oncology. He described how clinicians and patients are not taking advantage of the newer technologies. People are not being genotyped enough. A lot of patients in Utah aren't getting the testing they should get. Mark believes that this might be because patients are reluctant to undergo the genetic testing they should. Lack of genetic information may lead to a lot of inaccurate and expensive therapies and procedures. People

receive expensive immunotherapy that isn't what they really need because the true cause of their sickness is undetected.

Mark also explained why the approach required guardrails, especially to use and share genetic information. Patients, providers, payers, and politicians all have their own concerns. Genetic information can be used to unfairly discriminate against or stigmatize individuals on the job. Some genetic traits may be more common in certain ethnic or racial groups, leading to disproportionately burdened groups. Governments might stigmatize individuals. There is a concern of employers trying to avoid hiring people who might take sick leave, or resign early, or file for workers' compensation, or use health care benefits excessively. It may sometimes be appropriate to do genetic testing to protect workers with specific susceptibility from certain risks. There need to be laws that limit the disclosure of genetic information. Genetic Information Nondiscrimination Act makes it unlawful to discriminate on the basis of genetic profiles in regard to health insurance and employment. Health Insurance Portability and Accountability Act prohibits group health plans from using health status-related factors in denying or limiting eligibility for coverage or charging. The Americans with Disabilities Act provides some protections against disability-related genetic discrimination in the workplace. The 1964 Civil Rights Act stated that Genetic discrimination based on racially or ethnically linked genetic disorders could be construed as consulting unlawful race or ethnicity discrimination.

Seraphine asked how to bring testing to mainstream preventative care and help patients understand benefits and their fears. Mark said he would defer to Sarah's presentation. She then asked about genetic testing being used in criminal investigations. Mark said it might be possible to discover an individual's criminal activity with a family member's DNA.

Sarah Woolsey said this could help individuals find family members unknown otherwise. There is potential for familial discord. This could lead to legal declarations of financial responsibility or divorce. Trisha asked about implications for mental health. Sarah Woolsey said her research has found a link between marijuana use and schizophrenia. Mark Hiatt mentioned Navina's message about Utah's Genetic testing privacy act. It gives restrictions to employers. It restricts health insurers as well. Chris Klomp asked Mark if there is any best-in-class legislation he would consider studying. Mark says he thinks Utah is better than most places.

Ken Shaker shared his views on genetic testing and said it might not be as helpful as Mark Hiatt touted. He pointed out that a lot of testing is very expensive. He said genetics is not a perfect encompassing solution and that there's a lot of unanswered questions. Excluding health plans from having information might cause problems. He mentioned the biggest threats to the genetic environment are costs of these tests and that employers are wanting to reduce their health care costs. Health plans want to prevent employer groups from excluding genetic coverage. Mark agreed that some tests are not justified in their price. He said he is more focused on the confidentiality aspect.

Ken pointed out that health plans are often prevented from having certain information, which sometimes has unintended negative consequences. Ken believes nobody should be barred from buying insurance, but the genetic information could still be helpful to the insurance company to design a benefit structure beneficial to patients. Ken stated that there are countries that have passed laws that the person who is the origin of the information has a right to it and a right to be forgotten and have information deleted. In the United States, he said, we have a more complicated system with more

contracts and such. Terms of service can be complicated. He suggested there should be different classifications of rules for different use cases depending on the purpose of using the data.

Sarah Knight presented next. She is a psychologist in the Division of Epidemiology at the Department of Internal Medicine at University of Utah. She has researched the consumer viewpoint on genomics. She presented on Consumer values and preferences for genome sequencing and precision medicine. She studies how consumer decisions can align with health care services and policies to incorporate consumer preferences. After a 15 year career as a clinical psychologist, she is now a health services researcher and social scientist. Her focus is on health decision-making in cancer and genomics. She has received funding from the VA, the Department of Defense, the National Cancer Institute, the National Human Genome Research Institute, and the National Institute of Health. Her research also emphasizes stakeholder engagement. She is also a co director of the Community Collaboration and engagement team at University of Utah. She has previously done studies on hereditary colorectal cancer and the value that people put on genomics knowledge. She has also studied the value that stakeholders put on genetics and genomics. She has also studied the slow adoption of Genomic services even when there's strong scientific evidence in favor of them. Colorectal cancer is an example that explains the slow adoption of genomic services. This has been apparent in multiple health care systems. She's going to focus on what consumers and patients think are important. When genome sequencing is done, it often finds useful information, but that was not why sequencing was done initially. There is debate among professionals on how these results should be disclosed. A lot of these determinations are made by experts rather than consumers. One concern of giving people results from their sequencing is that if they are told they are at a higher risk of a certain disease, they will have a lot of worry. There is currently a small workforce to handle the demand for services. They are trying to expand. Consumer research indicated demand for genomic services.

There is a debate between whether you sequence people with risk factors and symptoms or if you should sequence everyone. There are multiple reasons as to why you would do sequencing. These include diagnosis, treatment, monitoring, and detection of future risk. People are also uncertain about what findings should be reported, such as if you should only release findings related to the reason for the test. A newborn baby may have characteristics that are genetically based. There are changes in genes which are called variants. Mackley researchers found 44 articles reporting views of 11,566 stakeholders that were supported returning actionable findings. Potential recipients focus on their rights to information. Genetics professionals expressed a sense of responsibility.

Sarah mentioned that she is working on a research project on quantitative studies with a student. They're studying consumer desire for ancestry testing. The project is developing a bioinformatics pipeline to pull continental ancestry information for sequencing. This may inform the accuracy of sequencing. In the studies they've researched, 90% of people in the studies are interested in genome sequencing and possibly have it. The interest is very high for results that could be medically actionable but less high for results that are not medically actionable. The samples in these studies aren't very good at capturing underrepresented minorities. There are few studies where the people involved are a close match demographically to the country the study was done in.

In April 2010 she did a study with 355 participants. They were US residents aged 50 and older. They put sample subjects into hypothetical groups with combinations of Risk and privacy settings and were asked

what they were willing to pay. People were generally willing to pay high costs, especially if they were high risk. Subjects were willing to pay a lot of money to avoid a high chance of a false-negative test result. People also strongly wanted to avoid having life and health insurance companies receive results. People slightly preferred primary care doctors receiving the results over genetics professionals.

The best test that most people are willing to pay for is one with no chance of a false negative and results being shared with primary care doctor. The worst test that people are least willing to pay for is a test with a high chance of a false negative and results shared with life and health insurance companies.

A couple of town hall meetings were conducted in Alabama, where they were surveyed about what factors matter with genetic testing. The respondents said the researchers should work with public health departments and community health workers and partner with advocacy organizations. They said researchers should partner with small businesses like barber shops and also large businesses like the local Mercedez plant. They wanted information on results and a good timeline for the arrival of results. They believed there should be time spent preparing materials and be sensitive to the concern about insurance discrimination. They said researchers should be sensitive to peoples' abilities to handle the results. The respondents also recommended using plain language.

She organized focus groups of veterans who were asked about experience, knowledge, and interest in genome sequencing. A common finding from these focus groups was that having more information is better for making decisions. The veterans in this group were seeking a lot of information about genetics and how the information could be helpful.

The people from these focus groups did still have some privacy concerns but they still seemed to think the knowledge gained was valuable enough that they would want to be tested.

Utah Health Information Technology Environmental Scan

Navina announced that Matt Ahern and Jen Anderson, both from Medicaid, would brief about the Utah Health Information Technology environmental scan.

Mathew Ahern started with some background information. The federal government implemented a plan for Medicaid and Medicare to incentivize the adoption of electronic health records. This program is 90% funded by the federal government. A survey had been given to the group in advance. [Mark Dalley recommended that he go through the parts of the survey] The survey responses included data on clinic types, provider types, and facility types. There was information on EHR adoption, internal functionality of EHR, interoperability, and information on EHR obstacles and broadband access. Mathew asked if there were anything else they would like to look at. Sarah Woolsey said she would be interested in portal use, including remote patient monitoring, and study how patients are sending information to their providers. And how providers are using it. Sarah stated that portal use was in its infancy when this program started. Henry Gardner asked if the study was on a national level or just unique to Utah. Mathew said the survey was unique to Utah but they have used national information in the past to update funding documents. Navina asked when Matt would like feedback on the survey. Mat suggested that within a week would be good.

Mark Dalley asked if Cheyenne needed to add anything. She said no but she was interested in Sarah's idea about portals.

Wrap-up:

Mark asked if the next meeting might be in person. Navina said that might happen for the July meeting.